# **SUSSEX COUNTY**

# Cancer Control and Prevention Capacity and Needs Assessment Report Summary

December 2004

# **Funds and Support Provided By**



New Jersey Department of Health and Senior Services Center for Cancer Initiatives The Office of Cancer Control and Prevention

## **Notices:**

Medicine is an ever-changing science. As new research and data broaden our knowledge, conclusions may change. The authors and reviewers have endeavored to check the sources of information and to utilize sources believed to be the most reliable in an effort to provide information that is as complete as possible at the time of submission and generally in accord with appropriate standards. However, in view of the possibility of human error or changes in medical science, this work cannot be warranted as being complete and accurate in every respect. Readers are encouraged to confirm the information contained herein with other sources. Information concerning some of the sources of data, rationale for its utilization, acknowledgements of specific parties contributing to these efforts, as well as links to cancer-related information may be found at <a href="https://www.umdnj.edu/evalcweb/">www.umdnj.edu/evalcweb/</a>.

This county-level Report Summary summarizes the larger county report, which is a baseline evaluation of this county, performed as part of the Capacity and Needs Assessment initiative of the New Jersey Comprehensive Cancer Control Plan (<a href="www.state.nj.us/health/ccp/ccc\_plan.htm">www.state.nj.us/health/ccp/ccc\_plan.htm</a>), under the direction of the New Jersey Department of Health and Senior Services (NJDHSS) Office of Cancer Control and Prevention (OCCP) (<a href="www.state.nj.us/health/ccp/">www.state.nj.us/health/ccp/</a>), the University of Medicine and Dentistry of New Jersey (UMDNJ) (<a href="www.umdnj.edu/evalcweb/">www.umdnj.edu/evalcweb/</a>), and the Evaluation Committee of the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force Chair: Arnold Baskies, MD; Evaluation Committee Chair: Stanley H. Weiss, MD).

Comments may be sent to the author of the Report Summary, Dr. Michael L. Siman, at <a href="mailto:mlsiman@aol.com">mlsiman@aol.com</a>. Copies of any comments should also be sent to both: Ms. Knight <a href="mailto:peg.knight@doh.state.nj.us">peg.knight@doh.state.nj.us</a> and Dr. Weiss <a href="mailto:weiss@umdnj.edu">weiss@umdnj.edu</a>.

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# Suggested citation for this Report Summary:

Siman ML. Sussex County Cancer Capacity and Needs Assessment Report Summary, December 2004. In: *New Jersey Statewide County-based Cancer Capacity and Needs Assessment Initiative, 2003–2004*, Editors: Stanley H. Weiss (UMDNJ) and Margaret L. Knight (NJDHSS).

## *Prepared by:*

Michael L. Siman, PhD, mlsiman@aol.com

# On behalf of:

The Sussex County NJCEED Program

# *Under the guidance of:*

Stanley H. Weiss, MD, University of Medicine and Dentistry of New Jersey-New Jersey Medical School (UMDNJ-NJMS) and School of Public Health (UMDNJ-SPH) (Principal Investigator)

Marcia M. Sass, BSRN, MSN, ScD, UMDNJ-SPH

Susan L. Collini, MPH, UMDNJ-NJMS

Daniel M. Rosenblum, PhD, UMDNJ-NJMS

Judith B. Klotz, DrPH, UMDNJ-SPH







## With the assistance of:

- The UMDNJ Clinical Research Group David L. Hom, MS, Loretta L. Morales, MPH, Benita Negron
- The Battelle Centers for Public Health Research and Evaluation Joanne P. Abed, PhD, Jennifer Brustrom, PhD
- The New Jersey Department of Health and Senior Services: the New Jersey Cancer Education and Early Detection Program, the New Jersey State Cancer Registry, and the Center for Health Statistics.

## Reviewed and edited by:

Jung Y. Kim, MPH, UMDNJ-NJMS

Daniel M. Rosenblum, PhD, UMDNJ-NJMS

Stanley H. Weiss, MD, UMDNJ-NJMS and UMDNJ-SPH

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# Sussex County Cancer Capacity and Needs Assessment Report Summary

#### Introduction

The Office of Cancer Control and Prevention (OCCP) of the New Jersey Department of Health and Senior Services (NJDHSS), in conjunction with the mandate from the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force), is developing comprehensive capacity and needs assessment reports concerning cancer, individualized for each county in the state. This Report Summary highlights key findings in the Sussex County report.<sup>1</sup>

The Task Force released New Jersey's Comprehensive Cancer Control Plan (NJ-CCCP) in 2002.<sup>2</sup> Each county was commissioned to develop a comprehensive capacity and needs assessment report, as part of the initial implementation steps for the NJ-CCCP. The full Report and this Report Summary were developed under the direction of the University of Medicine and Dentistry of New Jersey (UMDNJ) and the Evaluation Committee of the Task Force, in furtherance of the NJ-CCCP (which can be found at:

http://www.state.nj.us/health/ccp/ccc\_plan.htm
Description
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The purpose of the capacity and needs assessment reports is to identify the major cancer issues affecting each county and the county's available resources, or lack thereof, for cancer prevention, screening, and treatment, and to propose recommendations for improvement. The Sussex County Report<sup>1</sup> analyzes the population demographics and the cancer incidence and mortality rates and distribution of stage at diagnosis for the seven priority cancers of the NJ-CCCP (breast, cervical, colorectal, lung, oral, melanoma, and prostate), as well as current resources available, in the county. These data guided the development of evidence-based recommendations and interventions to address cancer control priorities at local and state levels.

# **Section 1 – County Demographic Profile**

The demographic profile of Sussex County presented below is based on data summaries obtained primarily from the U.S. Census and the N.J. Department of Health and Senior Services.

#### Sussex County is a young county.

• Sussex County has the lowest percentage of seniors (persons aged 65+) of any county in New Jersey (9.1%) (Table 1.I.2).<sup>a,1</sup>

<sup>&</sup>lt;sup>a</sup> Tables and figures in parentheses refer to detailed supporting data found in the full report.

- The percentage of persons under 18 years old living in Sussex County is higher than the corresponding percentage for the state (28% vs. 25%) (Table 1.I.2).<sup>b</sup>
- The percentage of those aged 20–64 was virtually unchanged between 1990 and 2000 (Table 1.II.3).

# Sussex County is homogeneous – small populations of minorities and foreign-born and non-English-speaking persons.

- Whites makes up 96% of the county's population, compared to 73% statewide (Table 1.III.1).
- Over 94% of Sussex County's population was born in the United States, while 5.7% of its population is foreign born, compared to 82% native born and 18% foreign born for the whole state (Table 1.V.4).
- Racial minorities make up less than 5% of Sussex County's population (Table 1.III.1).
- The percentage of blacks in Sussex County (1%) is significantly lower than the percentage for New Jersey (14%; Table 1.III.1).
- Asians make up 1.2% of the county population (Table 1.III.1).
- Hispanic persons make up only 3.3% of the Sussex County population, compared to 13% of the state population (Table 1.IV.1).
- Almost 92% of Sussex County residents over five years of age speak only English, compared to 75% of the population statewide. Among those in the county who speak a language other than English, only 2.3% of the county's total population (3,125 persons) speaks English *less than very well* compared to 17.5% of the state population (Table 1.V.2).

#### Sussex County has an educated population.

• The percentage of Sussex County residents over 25 years of age with more than a high school education exceeds the corresponding percentage for the state (56.4% versus 52.7%). Only 2.9% of the county population has less than a 9<sup>th</sup>-grade education, compared to 6.6% of the state population (Table 1.VII.1).

### Sussex County residents are homeowners rather than renters.

- 83% of occupied housing units in Sussex County are owner-occupied (Table 1.VI.2).
- In Sussex County, only 14% of housing units are in multi-unit structures, compared to 36% statewide (Table 1.I.2).

Sussex County residents are better off financially than the average person living in New Jersey, but some important population groups have incomes that may affect their ability to obtain healthcare services.<sup>d</sup>

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<sup>&</sup>lt;sup>b</sup> In general, percentages in this report are rounded to two digits.

<sup>&</sup>lt;sup>c</sup> Hispanics and non-Hispanics may be of any race. Racial categories include both Hispanics and non-Hispanics.

- Median household income in Sussex County is more than \$10,000 higher than in New Jersey as a whole (Table 1.I.2).
- Compared to females, male householders have significantly higher incomes (Table 1.VI.3). This suggests that the 4,034 women who are heads of households (Table 1.VI.1) may be in a more precarious financial position and may be less likely to have health insurance and adequate disposable income for healthcare services.
- Persons living alone have lower incomes than persons not living alone, and those over 65 years of age have the lowest incomes (Table 1.VI.4). It is possible, then, that persons aged 65 and above who are more susceptible to cancer and those persons who live alone have less capability to pay for healthcare services.
- The percent of persons in Sussex County defined as being in poverty in 1999 was less than one-half that of the statewide average (4.0% versus 8.5%; Table 1.I.2).

# 6. Sussex County experienced a greater than average percentage growth for population and employment between 1990 and 2000.

- Sussex County's population increased by 10.1% during the years 1990–2000 compared to New Jersey's growth rate of 8.6 percent.
- Sussex County's non-farm private employment during 1990–1999 increased by 13.1% compared with 6.8% for the state (Table 1.I.2).

#### Sussex County is a rural area.

- Approximately 40 % of the county's population living in 21 of the 24 municipalities resides in rural areas (Table 1.II.1).
- There are 276.6 persons per square mile living in Sussex County compared with 1,134.4 statewide (Table 1.I.2).

## Sussex County has some discouraging health status indicators.

- The age-adjusted death rate in Sussex County in 2000 913.3 per 100,000 was higher than that of the state 852.4 per 100,000 (Table 1.X.1).
- Approximately 29% of the entire population smokes (Table 1.X.2).<sup>e</sup>
- The age-adjusted death rate for chronic lower respiratory disease in 2000 43.5 per 100,000 was higher than that of the state 34.1 per 100,000 (Table 1.X.3).
- The age-adjusted heart disease death rate in Sussex County -293.0 per 100,000 was higher than that of the state -269.4 per 100,000.
- Arthritis was more prevalent in Sussex County, where the age-adjusted prevalence rate was 29.9%), than it was in the state, where the corresponding rate was 27.2%. <sup>1</sup>

<sup>&</sup>lt;sup>d</sup> All figures for poverty, income, and employment are from the 2000 Census, but refer to the year 1999.

<sup>&</sup>lt;sup>e</sup>It should be noted that this figure needs to be reassessed with more recent data since it is based on a small random sample surveyed approximately 10 years ago.

# Section 2 – Overview of Overarching Issues

Detailed information regarding cancer screening, education, advocacy, treatment, palliation, and other activities has been collected to identify resources currently available in Sussex County. This information was included in the statewide Cancer Resource Database of New Jersey (CRDNJ). Standardized survey forms ("TELEforms") were designed and used to collect uniform information about cancer-related resources in all 21 of New Jersey's counties, including Sussex. Some 27 agencies in Sussex County participated in the 2003–2004 Cancer Resource Database of New Jersey (CRDNJ) survey. Existing problems and opportunities to assist development of an efficient and effective countywide continuum of cancer control programs and services are identified in the paragraphs that follow. Among the requirements for such a system are opportunities for collaborative activities among established institutions and facilities within the county and the joint development of new initiatives.

#### **Access and Resources**

#### **Overview**

Cancer services in Sussex County are informed and guided by a worldwide system of cancer research and known successful practices. State, national and, in certain situations, international programs, treatment plans, and referral opportunities are available to healthcare personnel and residents of Sussex County. It is not known how well Sussex County organizations involved in cancer control efforts share an understanding of the scope of available services. Similarly, it is not known how well residents and health and social service personnel within the county understand the local cancer control resources that are available. Such potential weaknesses support public critiques such as "lack of care continuity" and "fragmented care". The minimization of roadblocks to improving cancer control requires that the relevant individuals and organizations constituting the health system communicate, share policies and practices, and agree to coordinate and collaborate on activities with one another, as well as with other county institutions such as county departments of human services, offices on aging, local schools, libraries, and newspapers. These actions have the potential to facilitate development of a wellregarded comprehensive county cancer control plan. There is currently no comprehensive cancer control plan in Sussex County that is culturally sensitive and that reflects the complete health services continuum of prevention, early diagnosis, treatment, survivor care, and end-of-life care for all county residents. It is also necessary to consider Sussex County's needs in light of the national resources and best practices that may be included in any future plans to strengthen the county's cancer control system and achieve the goals of the New Jersey Comprehensive Cancer Control Plan.

#### National-level Infrastructural Support for Health Care Providers

The broader system that impacts Sussex County cancer control providers includes the following:

**Federal programs.** The National Cancer Institute (NCI) is the leading agency in the nation's effort to reduce cancer illness and death (see <a href="www.cancer.gov">www.cancer.gov</a>). It conducts and supports research for prevention, early diagnosis, and treatment to eliminate cancer or control it as a manageable chronic illness. The Cancer Institute of New Jersey (CINJ) in New Brunswick (<a href="http://cinj.umdnj.edu">http://cinj.umdnj.edu</a>) is the only NCI Comprehensive Cancer Center located in New Jersey and is familiar with the payment practices of New Jersey Medicaid. CINJ conducts research and provides outreach, education, and information that is available to health services professionals and consumers. Four additional NCI Comprehensive Cancer Centers are located in neighboring states, two in New York City and two in Philadelphia.

NCI provides cancer information to providers and consumers nationwide through the Cancer Information Service (CIS). New Jersey, Delaware, and Pennsylvania comprise the CIS Atlantic Region located at Fox Chase Cancer Center in Philadelphia. The service is most famous for its toll-free information line 1-800-4-CANCER. However, of potential value to Sussex County cancer control planners, the CIS Partnership Program supplies staff to local planning efforts to share their expertise in designing, implementing, and evaluating cancer control programs. Additional CIS programs include the *Physicians Data Query (PDQ)*, an NCI database available to health professionals and the general public that contains current information about cancer prevention, treatment, complementary and alternative medicine, clinical trials and genetics, and *Special Population Networks for Cancer Awareness and Training (SPNs)* – a report that contains information about SPN projects that also may assist local planning efforts.

The National Comprehensive Cancer Network (NCCN) is a voluntary alliance of cancer centers that are recognized for their expertise. As a major contribution to cancer care, the NCCN develops, updates, and disseminates *Clinical Practice Guidelines in Oncology*, which is widely recognized as the current standard of treatment for specific cancers. NCCN also works with the American Cancer Society (ACS) to provide reader-friendly versions of the *Clinical Practice Guidelines in Oncology* for most cancer patients. NCCN Centers in the New Jersey area include Memorial Sloan Kettering Cancer Center in New York City and Fox Chase Cancer Center in Philadelphia.

The American College of Surgeons (ACoS) Commission on Cancer (CoC) Approvals Program is helping to develop a nationwide continuum of cancer care. This program recognizes facilities that provide a full range of medical and non-medical supportive services for cancer care through a multidisciplinary approach. St. Clare's Hospital in Sussex (Sussex County), with additional locations in Denville and Dover in Morris County, is approved as a Community Hospital Comprehensive Cancer Program. Newton Memorial Hospital in Newton is approved as a Community Hospital Cancer Program. (The full report contains criteria for all approval categories established by ACoS.)

Clinical trials. Clinical trials are medical studies designed to test new treatments or new ways to use an existing treatment. Sponsors of clinical trials can include individuals such as doctors, institutions such as hospitals, and drug companies and federal agencies such as the National Institutes of Health (NIH), the US Food and Drug Administration (FDA), and the Department of

Defense (DoD). The extent to which Sussex County residents are aware of opportunities for participation in clinical trials is not known.

New Jersey Cancer Trial Connect (<u>www.njctc.org</u>) is operated by the Cancer Institute of New Jersey (CINJ). It provides information about cancer clinical trials available in the state.

The Physician Data Query (PDQ) database mentioned earlier can be accessed through the NCI at <a href="www.cancer.gov/search/clinicaltrials/">www.cancer.gov/search/clinicaltrials/</a>. The general public can call 1-800-4-CANCER for live assistance in English and Spanish to search for clinical trials listed on the PDQ that meet their needs. Health professionals can email requests for clinical trial information to the CancerNetService Center (pdqsearch@cips.nci.nih.gov) or call 1-800-345-3300.

The Coalition of National Cancer Cooperative Groups, Inc., is a non-profit organization that maintains <a href="www.CancerTrialsHelp.org">www.CancerTrialsHelp.org</a> to help people understand cancer treatment options, especially clinical trials.

The Cancer Institute of New Jersey (CINJ) must provide clinical trials since it is approved by NCI as a Comprehensive Cancer Center and by the American College of Surgeons as a Comprehensive Cancer Program. Locally, Morristown Memorial Hospital (approved by ACoS as a Teaching Hospital Cancer Program [THCP]) and St. Clare's and Chilton Memorial Hospitals (approved as Community Hospital Comprehensive Cancer Programs [COMP]) also must provide cancer trials.

On January 1, 1997, the **Veterans Administration (VA)** and NCI agreed to provide NCI-sponsored prevention, diagnostic, and treatment clinical trials in VA hospitals nationwide. More information needs to be developed for Sussex County residents regarding the VA healthcare system in New Jersey.

#### Comprehensive Cancer Planning Activities in Sussex County

Although Sussex County does not have a comprehensive plan to address the cancer burden that exists within its borders, certain service providers are taking steps toward developing such a document. The Sussex County Cancer Coalition, initiated in December 2003, has representatives from more than 20 different constituencies/organizations and the community.

The Coalition has identified two priorities:

- Developing a comprehensive countywide cancer plan for Sussex County.
- Initiating an improvement project in the near future.

#### **Transportation**

A current needs assessment survey completed by the County Human Services Advisory Council (HSAC) reported that transportation is a top-priority need in Sussex County. A 1995 Sussex

Community Health Survey indicated that 3.9% of the county's population (approximately 14,000 residents) experienced difficulty in accessing or inability to access medical care due to transportation problems. As stated earlier, this figure needs to be reassessed with more recent data since it is based on a small random sample. The Sussex County Planning Division is currently producing a new comprehensive transit plan that will summarize the transportation needs of the county. A draft document was anticipated for early 2004.

#### **Employers**

Major employers in Sussex County have collaborated with St. Clare's and Newton Memorial Hospitals to provide employee health education, health fairs, and free publicity for local health initiatives.

#### **Comprehensive School Education**

New Jersey state law mandates general health education related to cancer in the public schools. However, it specifically mandates instruction in female breast self-examination for students in grades 7 through 12. In Sussex County, although there is a County Board of Education, each individual school district is responsible for implementing the guidelines and activities mandated by the state. The CRDNJ Survey provides some insight into how extensively such cancer education is provided. Of all respondents (15 schools representing grades 5–12), only a minority reported providing education on breast (4 schools) and testicular (3 schools) self-examination. The majority of respondents either responded that this material is not applicable or chose not to answer the question.

In May 2004, some representatives from Sussex County school districts attended professional staff development provided by the American Cancer Society (ACS) and the state's Departments of Agriculture (NJDA), Education (NJDOE) and Health and Senior Services (NJDHSS) that focused on the NJ-CCCP. The workshop addressed K–12 core curriculum and provided materials that can be duplicated. The program stimulated a school nutrition project in the Sussex/Wantage district that is assisted by a community team that includes the ACS, the American Heart Association, and the Sussex County Center for Prevention and Counseling Information.

## Palliation/Quality of Life/Survivorship

Persons with cancer generally live longer today that they did years ago. More persons are now alive who have cancer and who therefore require many services for cancer treatment and other conditions that affect their comfort and longevity. Central to survivorship are the pain control services offered at both hospitals in the county and additional sources of information about pain control provided through the ACS program, The New Jersey Pain Initiative, the National Chronic Pain Outreach Association, Inc., and the Pain Institute jointly administered by the University of Medicine and Dentistry of New Jersey and Robert Wood Johnson University Hospital in New Brunswick. In general, it is not well known how extensively resources for

<sup>&</sup>lt;sup>f</sup> A source of "best practice" information.

survivors other than pain control are provided to Sussex County residents, nor is much known about the standards and protocols of service performance in Sussex County.

End-of-life care is provided in Sussex County by the Karen Ann Quinlan Hospice Center in Newton. The Center has an average daily census of 35 patients, about two-thirds of whom are cancer patients. The program offers in-home and nursing home care. Hospice issues include transportation, lack of funding/reimbursement for services, and the need to educate physicians regarding hospice to overcome a continued reluctance to refer patients. Compassionate Care is a for-profit hospice service that provides residential care in a 14-bed facility at St. Clare's Hospital in Dover, Morris County.

#### **Providers and Treatment**

Resources in Sussex County are presented below, organized according to the continuum of cancer control, which includes prevention, early diagnosis, treatment, survivor care, and end-of-life care

#### Prevention

Prevention is the reduction or elimination of a disease by measures intended to prevent or avoid onset of the disease. A number of cancer prevention services are available in Sussex County and are being developed through implementation of the NJDHSS Comprehensive Tobacco Control and Cancer Education and Early Detection Programs. Examples include tobacco control services such as environmental tobacco smoke (ETS) control, smoking cessation programs (including the Quitcenter at Newton Memorial Hospital), professional education opportunities, and community action/advocacy programs. NJCEED workers in Sussex County have been provided with several cancer education videos directed to minority populations and have access to NJCEED's New Jersey's Circle of Friends program materials designed for presentation in senior housing centers and nutrition sites, churches, worksites, and other locations during monthly or quarterly meetings. During October, NJCEED partners with libraries in the state and Wal\*Mart stores to promote breast cancer awareness. A similar collaboration with Rite Aid Pharmacies promotes mammograms in May.

#### Early Detection or Secondary Prevention

Early detection is the reduction or elimination of a disease by interventions in asymptomatic and at-risk individuals identified prior to development of the clinical manifestations of disease.

Services provided to the private payer/insured population. Within this population, early detection of cancer is achieved through scheduled visits or "wellness exams" sought from primary care providers by their patients. Primary care cancer screenings are usually provided by physicians such as internists, family medicine practitioners and obstetrician/gynecologists. Cost coverage by health insurers for such exams varies, although most insurers, including NJ Family Care providers, include the screening exams that are covered by Medicare Part B.

<u>Mammography</u>. In Sussex County, mammography is available to private pay or insured individuals from three providers whose facilities are U.S. Food and Drug Administration (FDA) Certified. The facilities are guided by the Mammography Quality Standards Act, which ensures that mammography is safe and reliable and that consumers receive uniformly high-quality services from facilities throughout the United States. The providers – Saint Clare's Hospital, Newton Memorial Hospital, and The ImageCare Centers in Newton, Vernon and Sparta – can perform approximately 400 mammograms each week.

Services provided to the economically disadvantaged population. As stated above, the NJDHSS provides services through NJCEED. This program is funded by the Centers for Disease Control and Prevention in each of the state's 21 counties. NJCEED provides screening for breast, cervical, colorectal, and prostate cancers. The program is coordinated in Sussex County by St. Clare's Hospital and is scheduled to be available in the county at all health departments. Screening services for women include clinical breast and pelvic examinations, Papanicolaou ("Pap") tests and breast self-exam instruction. Services for males include Prostate Specific Antigen (PSA) tests for prostate cancer and, for men with symptoms, breast cancer diagnostic tests. Fecal Occult Blood Testing (FOBT) to screen for colorectal cancer is available to both sexes. Further diagnostic testing is performed as needed. Tracking, follow-up, and case management are also provided.

<u>Local health departments</u>. The four local health departments in Sussex County provide male/female cancer screening opportunities similar to the NJCEED program for residents of the municipalities they serve. Local public health nurses provide program follow-up services. The health departments also report environmental health and tobacco control activities as part of cancer control. Health departments provide services to municipal residents based on contractual agreement with particular municipal boards of health.

County screening capacity. In addition to the two Sussex County hospitals and four health departments, there are several privately owned screening facilities. Considering the reported capability of all facilities in the county, it is estimated that more than 50,000 screenings of various types could be completed each year, including 28,824 screenings for breast cancer (15,140 mammography, 13,684 breast exam), 10,520 colorectal (1,250 digital rectal examination or DRE, 1,394 FOBT, 1,476 colonoscopy/sigmoidoscopy), 7,674 cervical, 6,647 prostate, 3,650 oral/oropharyngeal, 1,180 melanoma, and 50 lung.

#### Treatment and Care

Treatment is the reduction or elimination of a disease by interventions in symptomatic individuals identified after development of clinical manifestations of disease.

<u>Hospital care.</u> Acute cancer treatment is provided through the county's two hospitals – St. Clare's and Newton Memorial – both of which are approved by the American College of Surgeons and provide a full range of cancer care services.

<u>Community-based care.</u> The American Cancer Society, a nationwide, community-based voluntary health organization, dedicated to helping everyone who faces cancer through research, patient services, early detection, treatment, and education, is a major source of

information regarding cancer in the United States and, more specifically, in Sussex County. The organization's website at <u>www.cancer.org</u> provides immediate access to local offices and their programs through a homepage navigation system that searches the agency's resources by zip code or city and state. Free telephone support is available any time through its national call center<sup>g</sup> (1-800-ACS-2345 ext. 1).<sup>2</sup> Patients and others can obtain referrals to local cancer resources as well as to a local "patient and family services director/coordinator" who may be able to serve as a "patient navigator." ACS services in Sussex County are provided through its offices in Parsippany, Morris County.

Additional resources include Planned Parenthood of Greater Northern New Jersey, the New Jersey Self-Help Clearinghouse, a non-profit service of Saint Clare's Health System, the Coalition of National Cancer Cooperative Groups that provide help regarding specific cancers, the School Health Services Guidelines developed by NJDOE and NJDHSS to explain mandated school health services required to support continuing participation of children with chronic illness or disabilities in school, and the Cancer Resource Database of New Jersey (CRDNJ) that was developed as part of the current capacity and needs assessment process. In Home Health Services in Sparta provides home healthcare in the county. The ACS Man to Man Prostate Cancer Support Group is located at the Community Cancer Connection in Sparta. Availability of the Roman Catholic Paterson Diocese Health Ministry program to Sussex county residents can be determined through Hope House.

#### Advocacy

At present, there are no specific Sussex County-centered advocacy efforts being conducted on behalf of the cancer needs of county residents. The New Jersey Group Against Smoking Pollution (GASP) and ACS are advocates for specific cancer-related action.

#### **Nutrition and Physical Activity**

Cancer-specific nutrition programs do not appear to be widespread in Sussex County. However, as mentioned earlier, the Center for Prevention and Counseling, ACS, the American Heart Association, and Sussex/Wantage schools are cooperating to provide a school nutrition project.

The New Jersey Food Stamp Nutrition Education Program (FSNEP) was established to provide nutrition education to limited-resource adults, seniors, food stamp recipients and children in school systems that have at least 50% of students receiving free- or reduced-cost school lunches. The program provides nutrition education through community assistant paraprofessionals that are peer educators hired from the indigenous population. Interviews with school nurses in the county identified obesity as a health risk for Sussex children, with a primary contributor being the children's sedentary lifestyles. Nurses interviewed as part of the CRDNJ survey are in agreement that the current health programs conducted in the public schools do not adequately address the increasingly problematic rise in obesity.

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g The national call center takes 1.2 million calls per year. See <a href="http://www.cancer.org/docroot/ESN/content/ESN\_3\_1X\_ACS\_National\_Cancer\_Information\_Center.asp?sitearea=ESN">http://www.cancer.org/docroot/ESN/content/ESN\_3\_1X\_ACS\_National\_Cancer\_Information\_Center.asp?sitearea=ESN (accessed 9/22/2004).</a>

#### **Childhood Cancer**

The National Childhood Cancer Foundation (<u>www.nccf.org</u>) reports that an estimated 75% of children with cancer can now be cured. The cure rate is attributed to research and networking among members of the Children's Oncology Group (COG). However, each year about 2,300 children between ages 1 and 20 die from cancer. This figure is higher than all childhood deaths from asthma, diabetes, cystic fibrosis, and AIDS combined.

The Valerie Fund (<a href="www.valeriefund.org">www.valeriefund.org</a>) provides comprehensive cancer care, including medical, acute healthcare and social services close to home for children in New Jersey. All Valerie Fund Centers participate in the COG and provide services through a multi-disciplinary team. Morristown Memorial Hospital is a Valerie Fund Center. Primary care physicians in Sussex County who are treating a child with a cancer problem that requires close observation and/or further treatment can refer their patient to the Pediatric Oncology Program at Morristown Memorial Hospital. Staff at the program serve as consultants and keep the primary physician apprised regarding the patient's care and progress. The Valerie Network also includes a Children's Satellite Center in Sparta.

#### **Resources External to the County**

The American College of Surgeons approval standards discussed earlier appear to be defining a continuum of cancer care with a definite hierarchy of services. In Sussex County, the hierarchy among acute care facilities ranges from *Community Hospital Cancer Program* to *Community Hospital Comprehensive Cancer Program*. The next level of approval, *Teaching Hospital Cancer Program (THCP)*, is available at Morristown Memorial Hospital, Morristown. As an *NCI-designated (NCIP) Comprehensive Cancer Program*, the Cancer Institute of New Jersey (CINJ) at the Robert Wood Johnson Medical School in New Brunswick provides a higher level of cancer care than these other facilities. Morristown Memorial Hospital is affiliated with the University of Medicine and Dentistry of New Jersey. Such affiliation might facilitate referral for further treatment to CINJ. Childhood cancer care might follow a similar pattern since CINJ also is a COG facility.

Several major community-based Sussex cancer service providers such as ACS, Planned Parenthood, and Hope House are located in Morris County; this suggests there are common services delivered regionally to Morris and Sussex counties. There are also seven out-of-county hospice providers that serve residents of Sussex County.

#### Section 3 – Cancer Burden

All incidence<sup>3</sup> and mortality<sup>4</sup> rates cited herein are per 100,000 and age-adjusted to the 2000 U.S. population standard<sup>5</sup>. All county and state rates (unless identified otherwise) are average annual rates during 1996–2000. For simplicity, the 1996–2000 average annual age-adjusted incidence or mortality rate hereinafter will be abbreviated and referred to as incidence or mortality rate, respectively. The reason the five-year average has been routinely used is that the small number

of cases in a single year leads to statistical variations that are not generally meaningful. For U.S. incidence rates, 1999 or 2000 rates were used. Unless otherwise specified, all rates are for invasive cancer only.

#### **Overall Cancer Burden**

• For the five-year period ending in 2000, Sussex County had an incidence rate for all cancer sites combined (485.2 for females, 637.8 for males) that was notably higher than that of New Jersey (453.7 for females, 628.7 for males).

## **Specific Cancer Types**

Sussex County statistics on prevalence, incidence, and mortality for all seven cancer types are presented in the summary table that follows.

Summary of Selected<sup>a</sup> Age-Adjusted<sup>b</sup> Sussex County Cancer Statistics, 1996–2000<sup>c</sup>

	Estimated Prevalence <sup>d</sup>	Incidence per 100,000 <sup>e</sup>	Mortality per 100,000 <sup>e</sup>
All cancers, Sussex County			
Male	1,818	637.8	264.0
Female	2,864	485.2	190.0
NJ-CCCP Priority Cancer by Gender			
Breast, female	1,093	138.4	32.8
Cervical, female	105	8.6	3.3
Colorectal, male	244	94.3	34.6
Colorectal, female	302	60.3	19.8
Lung, male	67	94.5	78.0
Lung, female	91	65.0	50.2
Melanoma, male	116	19.9	4.5
Melanoma, female	190	16.3	2.5
Oral/Oropharyngeal, male	54	12.8	3.3
Oral/Oropharyngeal, female	56	9.6	1.0
Prostate, male	654	180.7	27.5

<sup>&</sup>lt;sup>a</sup> Based upon the NJ-CCCP.

<sup>&</sup>lt;sup>b</sup> Age-adjusted to 2000 U.S. Census population standards. Age-adjustment is used to describe rates in which statistical procedures have been applied to remove the effect of differences in composition (specifically, variations in age distribution) of the various populations. This is important in order to portray an accurate picture of the burden of cancer, since cancer is known to disproportionately affect persons of differing ages.

<sup>&</sup>lt;sup>c</sup> Rates are average annual rates during the time period 1996 through 2000.

<sup>&</sup>lt;sup>d</sup> Prevalence is the measurement of burden of disease in the population at a particular point in time. Within this report, it represents the number of people alive who have ever been diagnosed with the disease. Prevalence figures given here are rough theoretical estimates, based on a number of assumptions, and computed by applying national prevalence-to-incidence ratios to Sussex County's average annual crude incidence counts for the five years 1996–2000, separately for each gender. Actual prevalence is likely to be of the same order of magnitude as the estimate. <sup>6</sup> Incidence and mortality are gender-specific, age-adjusted annual rates, not counts. A rate at least 10% higher than the corresponding state rate is shown in bold italics.

f "All cancers" represents the sum of all invasive cancer during the time period, not just the seven cancers presented in detail below.

Cancers for which county incidence rates were at least 10% higher than state rates include: colorectal (male and female), lung (female), melanoma (female), and oral/oropharyngeal (female). Cancers for which county mortality rates were at least 10% higher than state rates include colorectal (male), lung (female), and melanoma (female).

#### **Breast Cancer**

- Nationally, female breast cancer was the most common cancer among women, comprising an estimated 31% of new cancer cases and causing 15% of cancer deaths in U.S. females.
- Over the time period 1996 through 2000, inclusive, the total number of women diagnosed with invasive breast cancer was 478. This is the total incidence of new cases over the five-year period. Thus, the annual incidence was 96 cases per year.
- There are no statistically significant trends for either Sussex County or New Jersey over the latest five-year period (1996–2000), indicating stable breast cancer incidence rates.
- Incidence rates grouped according to age followed a similar pattern to that for New Jersey: breast cancer incidence rates increased with age.
- Sussex County's average 1996–2000 female breast cancer mortality rate was 32.8 per 100,000. Thus, this rate would need to decrease by 34% over the next 7 years in order to meet the *Healthy New Jersey 2010*<sup>7</sup> objective for breast cancer mortality as recalculated using the 2000 U.S. population standard, 21.5 per 100,000.<sup>8</sup>
- The challenge of early breast cancer diagnosis is exacerbated in Sussex County where late stage diagnoses were at least 6 percentage points higher than in New Jersey or the U.S. (35% for the county versus 29% for the state and 27% for the nation).
- The *Healthy New Jersey 2010* target for early diagnosis of breast cancer is 75%. With Sussex County's average early diagnosis percentage at 62% during 1996–2000, meeting the target would require a 21% increase in the percentage of early diagnoses over the next seven years.
- New Jersey data reveal that white women had the highest incidence of breast cancer in every age group. In Sussex County, as in the state as a whole, this rate increased consistently with age, making the senior population (those aged 65 and over, particularly those aged 75+) the target population.
- Among 3,923 New Jersey women aged 50 and over who were interviewed from 2000 through 2002, 78% reported having had a mammogram within the past two years. As there were 19,456 women aged 50 and over in the county, the BRFSS data suggest that roughly 7,588 mammograms were conducted in this age group alone. Continued outreach and education aimed particularly at those who have not had mammograms is a priority.

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<sup>&</sup>lt;sup>h</sup> In situ cancers are not included in this or other totals.

#### Cervical Cancer

- There was a statistically significant decrease in cervical cancer incidence in New Jersey over the latest five-year period (1996–2000), but there were too few cases in Sussex County to ascertain whether the same trend existed on a county level.
- Cervical cancer in Sussex County was most common among the population aged 75 and over (incidence rate of 30.6, based on 6 cases); this rate was approximately three times higher than the rate for age groups below 65, although the counts were too small to evaluate the significance of these figures reliably.
- The average cervical cancer incidence rate for Sussex County during 1996–2000 was 8.6 per 100,000. This rate must decrease by 21% over the next 7 years to meet the *Healthy New Jersey 2010*<sup>7</sup> target for cervical cancer incidence of 6.8 per 100,000, as recalculated using the 2000 U.S. population standard.<sup>8</sup>
- The percentage of women in Sussex County whose invasive cervical cancer was detected early appears to be lower than the corresponding percentages for New Jersey and U.S. women (35.5% for the county versus 47.1% for the state and 54.4% for the nation), although counts in Sussex County were too low to attribute any significance to this difference.
- The highest percentage of distant-stage cervical cancers in New Jersey was detected in the over-50 age groups (ages 50–64 and 75+).
- Papanicolaou ("Pap") tests, which detect some precancerous as well cancerous lesions, are covered by most private and public health insurance. Some companies have moved to cover a more sensitive and specific screening test, the AutoPap, which uses a thin preparation of cells along with computer-assisted technology.
- Human papillomavirus (HPV), a sexually transmitted disease, is the most significant risk factor for developing cervical cancer; recommendations for the incorporation of HPV testing as part of a pelvic examination have been developed by the American College of Obstetricians and Gynecologists. Risk factors for cervical cancer include ever being sexually active, lack of routine screening, early onset of sexual intercourse, a history of multiple partners, a history of sexually transmitted infections (especially HPV), obesity, and smoking.
- To reduce cervical cancer mortality and incidence in Sussex County, the National Cancer Institute's Consumer Health Profiles identified three high-priority geographic target areas: Newton, Franklin, and Sussex.<sup>j,13</sup>

<sup>&</sup>lt;sup>1</sup> For example, the ViraPap<sup>TM</sup> will detect which strains of HPV DNA, if any, are present.

UMDNJ and each county by the National Cancer Institute's Atlantic Region Cancer Information Service, along with ongoing technical support. (More information can be obtained from: 1-800-4-CANCER.) The medically underserved refers to individuals who lack access to primary care either because they are socioeconomically disadvantaged and may or may not live in areas with high poverty rates or because they reside in rural areas. The term also refers to individuals that reside in geographic areas where the Index of Medical Underservice (IMU) is 62 or less. The IMU is a weighted score derived from four variables: the ratio of primary medical care physicians per 1,000 population, infant mortality rate, percentage of population below the federal poverty level, and the percentage of the population aged 65 years and older. The data categorize the U.S. population into 62 groups based upon characteristics such as geography, demographics, lifestyle, and socioeconomic status. Within these 62 groups, 30 are classified as medically underserved.

#### Colorectal Cancer

- Over the five-year period 1996 to 2000, there was a statistically significant increase for Sussex County female colorectal cancer incidence (47.3 to 66.6 per 100,000 population).<sup>3</sup> There was no corresponding statistically significant trend for New Jersey over this period, indicating that the incidence rate for the state remained stable.
- For both males and females in Sussex County, as in New Jersey, the incidence of colorectal cancer increased consistently with age; the highest incidence rates were observed for individuals 75 years of age and older. The incidence rates for males were higher than those for females for all ages and also for each individual age group except the 15–39 group; in this age group, colorectal cancer is so rare that meaningful county-level comparisons were not possible.
- Mortality data from the National Cancer Institute (NCI) shows that for the period from 1996 to 2000, Sussex County's overall mortality rates for both males and females were similar to the New Jersey rates. Over this time period, the rate for females fell and the rate for males remained stable. During this time, the average mortality rate for males was almost twice that of females (34.6 versus 19.8 per 100,000 population, age-adjusted).
- Sussex County data on stage of diagnosis for colorectal cancer in both males and females for 1996–2000 indicates that more cases were diagnosed at a late stage (regional or distant) than at an early stage (localized or *in situ*). For females, 48% of cases were diagnosed at a late stage versus 41% at an early stage; for males, 48% of cases were diagnosed at a late stage versus 40% at an early stage.
- Given the effectiveness of screening and the higher colorectal incidence rates in the older age groups, colorectal cancer prevention and control efforts should focus on everyone in the county over 50. Special attention should be directed at males because they have much higher incidence and mortality rates than females.

#### Lung Cancer

- Although lung cancer is the third most common cancer in the U.S. (after breast and prostate cancers), more people die from lung cancer than any other type of cancer. <sup>14</sup>
- Reflecting the national trend of decreasing lung cancer incidence among men, New Jersey has seen a decreasing incidence in this cancer since the late 1980s. In contrast, female lung cancer incidence rates have generally been stable in both New Jersey and the United States. However, during 1996–2000, incidence rates of lung cancer among females in Sussex County increased by an average of 4.4 per 100,000 per year, although this increase was not statistically significant.
- For both males and females in Sussex County, the incidence of lung cancer increased with age, although among males the rate in the 65–74 age group (558.9) was marginally higher than that in the 75+ group (556.0). The overall lung cancer incidence rate for males was substantially higher than the rate for females (94.5 versus 65.0 per 100,000 population).
- Mortality data show that for the period from 1996 to 2000, Sussex County's overall lung cancer mortality rate has been stable and was similar to the overall New Jersey rate. However, there was a striking gender difference in lung cancer mortality rates: the rate for males fell while the rate for females rose. Over the five-year period, the average

mortality rate for males was approximately one and one-half times that for females (78.0 and 50.2 for males and females, respectively). Because of these trends, the National Cancer Institute assigned a low priority index to lung cancer for males in Sussex County (eight out of nine) but gave the very highest priority index to female lung cancer (a rating of one). <sup>15</sup>

- Because Sussex County's average 1996–2000 lung cancer mortality rate was 61.5, lung cancer mortality over the next seven years would need to decrease by 26% in order to meet the *Healthy New Jersey 2010* <sup>7</sup> target (4C#11 as recalculated using the 2000 standard population: reduce the age-adjusted death rate from lung cancer to 45.3 per 100,000 for the total population).
- There are now no screening recommendations for lung cancer, as no screening test has been found effective in reducing morbidity and mortality.
- Because lung cancer is overwhelmingly the result of a history of smoking, the prevalence of smoking in Sussex County remains a significant problem. Based on survey data collected in 2003, there has been no progress in reducing the percentage of county residents who smoke.<sup>16</sup> Of those who responded to the survey, 28% reported that they smoke daily, and an additional 14% reported smoking on some days.

#### Melanoma

- Skin cancer is the most common cancer in the United States, affecting approximately one million Americans every year. Although melanoma is by far the most aggressive form of skin cancer, it constitutes only a small fraction of all skin cancers.
- For both males and females, melanoma incidence rates over the past five years showed no significant changes for either Sussex County or New Jersey.
- Sussex County males had a somewhat higher melanoma incidence rate than females (19.9 versus 16.3 per 100,000 for males and females, respectively). The highest incidence rate was found among males 75 years of age and older (96.0 per 100,000 population).
- The *Healthy New Jersey 2010* <sup>7</sup> target for melanoma incidence is 12.4 per 100,000 for the white male population and 7.7 for white females (both targets are recalculated using the U.S. 2000 population standard for age adjustment). Sussex County's average melanoma incidence rate during 1996–2000 was 20.3 for males; thus, in order to meet the target, this rate must decrease by 38.9% over the next seven years. For females, the melanoma incidence rate would need to decrease by 54% over the same time period to meet the target.
- Sussex County's average annual melanoma mortality rate among females for 1996–2000 (2.5 per 100,000) was higher than the New Jersey rate (1.9).
- The stage at which melanoma is being diagnosed in New Jersey is improving. Preliminary data for 2000 indicate that 88% of melanomas were diagnosed in the early stages (*in situ* and local) compared to 70% in 1995. <sup>11</sup>
- During 1996–2000, 79% of melanomas found in white females living in Sussex County were diagnosed in the early stages. This percentage was lower than the figures for New Jersey (83%) and the nation (90%). Unfortunately, the percentage of late-stage diagnoses (regional and distant) among Sussex County females was almost twice as high as the state and U.S. percentages (12.7% for the county versus 6.5% for the state and 7.5% for the nation).

- For Sussex County males, 77% of melanoma diagnoses were early stage; this was lower than the figure for New Jersey (81%). However, the percentage of late-stage diagnoses for Sussex County males was virtually the same as the percentage for males statewide (8.4% versus 8.2%).
- Among females both in Sussex County and statewide, the 65–74 age group had the highest percentage of melanomas diagnosed in the late stages (21%). The youngest Sussex County female group (15–39 years) had the highest percentage of melanomas detected in the early stages (93.8%). Opposite patterns were observed among Sussex County males. The highest percentage of late-stage melanoma was found in the youngest age group (15%), while the highest percentage of *in situ*/localized melanomas were found in the 50–64 age group (89%).
- In Sussex County, health departments and both hospitals offer skin cancer screenings throughout the year. The county capacity for melanoma screening (1,100 screenings annually) is not adequate to screen even the residents in the two priority age categories males 75 years and older (2,159 residents) and females 50–74 years of age (15,505).

#### Oral/Oropharyngeal Cancer

- New Jersey mirrors the national average for oral and oropharyngeal cancer incidence. Since the mid-1980s, New Jersey and U.S. incidence rates for oral and oropharyngeal cancer have been declining. Males have traditionally had higher incidence rates than females in New Jersey, although in recent years the gap narrowed, presumably due to the increasing number of women who began smoking over the past three decades.
- In Sussex County, incidence rates for 1996–2000 were 9.6 per 100,000 for females and 12.8 per 100,000 for males. The rate for males was lower than that for the state as a whole (15.7 per 100,000) while the county rate for females exceeded the New Jersey rate (6.4 per 100,000). Incidence rates of oral/oropharyngeal cancer increased dramatically with increasing age.
- The most significant indicator in predicting survival is stage of oral and oropharyngeal cancer at time of diagnosis. Cases diagnosed at an early stage have a five-year survival rate of more than 75%, while cases diagnosed in the late stages have a poor five-year survival rate (less than 25%). 17, 18
- The *Healthy New Jersey 2010* <sup>7</sup> target for early detection of oral cancer (Objective 4C#13) is to reduce the percentage of oral cancer diagnosed in the late (regional and distant) stages of disease to 40% for all males and 35% for all females. Since the percentages of late-stage diagnoses for Sussex County males and females were 61% and 47% respectively during 1996–2000, reaching these targets would respectively require 34% and 25% decreases in the percentages of late-stage diagnosis over the next seven years.
- Studies support the conclusions that too few people have regular oral and oropharyngeal cancer examinations and that too few dentists and physicians are performing routine oral and oropharyngeal cancer exams. Less than 15% of the general public reported being examined for oral cancer. It is critical, then, that we increase the number of Sussex County residents who receive oral cancer examinations, especially at recall visits.
- In Sussex County, only Newton Memorial Hospital offers screenings for oral and oropharyngeal cancer; none of the health departments provide screenings. Among

individuals aged 40 years and older in New Jersey, the majority of oral and oropharyngeal cancers were diagnosed at the late stage; hence males and females aged 40 years and older should be the priority groups for screening. The screening capacity of 3,650<sup>20</sup> annually in Sussex County is not sufficient to meet the priority groups' need.

#### Prostate Cancer

- Recent data show that, for the period from 1996 to 2000, Sussex County's prostate cancer mortality rate was both stable and similar to the overall New Jersey rate. Although Sussex County's rate was numerically lower than the state rate (27.5 vs. 32.9), this difference is not statistically significant. For this reason, the National Cancer Institute assigned a relatively low priority index six (out of a possible nine) to prostate cancer in Sussex County.
- The *Healthy New Jersey 2010* <sup>7</sup> target for prostate cancer mortality (Objective 4C#7) is to reduce the age-adjusted death rate of males from prostate cancer to 24.7 per 100,000 (as recalculated using the 2000 U.S. standard population for age adjustment)<sup>8</sup>. Because Sussex County's average 1996–2000 mortality rate was 27.5, reaching this target would require a 10.2% decrease in prostate cancer mortality over the next seven years.
- In New Jersey between 1995 and 2000, the annual proportion of cases diagnosed in the early stages of the disease (either *in situ* or localized) increased from about 61% in 1995 to about 76% in 2000. Although the proportion of prostate cancer cases diagnosed at an early stage during 1996–2000 in Sussex County was higher than the percentage diagnosed statewide (76% versus 72%), the county percentage was lower than the national percentage (90%).
- Age-group comparisons for prostate cancer diagnosis in Sussex County duplicate the patterns observed for New Jersey as a whole: the highest percentage of cases diagnosed in the distant stages (7.6%) was found for the oldest age group (75+).
- Sussex County had a lower percentage of distant stage diagnosis than both the state and nation.
- Although the black male population of Sussex County is relatively small (approximately 600 men), the dramatically higher prostate cancer mortality rate for this group more than twice the overall rate for the county identifies it as a target population.
- The risk factors for prostate cancer are inherent and therefore not preventable. Scientific consensus has not been reached on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. The Centers for Disease Control and Prevention does not recommend prostate cancer screening, but does recommend offering information about the potential harms and benefits of screening in order that men, their physicians, and their families can make informed decisions about screening.
- In Sussex County health departments and both hospitals offer prostate cancer screening throughout the year. The annual capacity of over 6,600 prostate cancer screenings<sup>20</sup> is not adequate to meet the screening need for the highest priority group, the approximately 31,000 men over 40 years of age.

#### Other Cancers

#### **HIV and HIV Associated Cancers**

- The human immunodeficiency virus (HIV) is the etiologic agent of the acquired immunodeficiency syndrome (AIDS) and is associated with the development of several specific cancers. <sup>11</sup> Sussex County ranks last amongst all New Jersey counties in the prevalence of HIV/AIDS. <sup>21</sup> Both healthcare providers and patients need to understand the risks associated with HIV/AIDS.
- The acquired immunodeficiency syndrome (AIDS) has been associated with cancer from the onset. Improved therapies have increased the lifespan of HIV and AIDS patients. It is estimated that approximately 4 out 10 people in developed countries with AIDS will develop cancer.
- In a study of New Jersey patients with AIDS, approximately 6% had cancer, and within this group, 17% had oral cancer. Since 1998, neoplasms are the top cause of death of those who have AIDS. <sup>23</sup>
- As of December 31, 2003, Sussex County had 117 persons living with HIV/AIDS. Cumulatively, there have been 205 cases of HIV/AIDS recorded in the county.<sup>24</sup>

#### **Bladder Cancer**

- In New Jersey, the overall incidence rate of bladder cancer<sup>k</sup> during 1996–2000 (26.2) was higher than in the U.S. (21.9). In the same five-year period, among all New Jersey counties, Sussex County had the highest bladder cancer incidence rate for men and women combined (31.0); this rate was significantly higher than the rate for New Jersey (25.3). Sussex County remained among the two or three counties with the highest incidence rate of bladder cancer in the state for men and women separately in 1997–2001. Mortality due to bladder cancer during 1997–2001 was higher in New Jersey (5.1) than in the nation overall (4.4). The American Cancer Society estimated that bladder cancer in 2003 would be the sixth most common cause of cancer mortality in the U.S. and the fifth most common in New Jersey. The American Cancer Society estimated that bladder cancer in 2003 would be the sixth most common cause of cancer mortality in the U.S. and the fifth most common in New Jersey.
- The greatest risk factor for bladder cancer is smoking. Smokers experience twice the risk of bladder cancer as nonsmokers. Smoking is responsible for about 48% of bladder cancer deaths among men and 28% of deaths among women.
- The incidence of urinary bladder cancer in New Jersey during 1996–2000 was over three and one-half times higher in men (45.3) than in women (12.8)<sup>28</sup>, similar to the pattern observed for the nation as a whole. This pattern continued both statewide and in Sussex County in 1997–2001; incidence rates among males were 53.4 in Sussex and 46.0 in New Jersey, while rates among females were 14.9 in Sussex and 12.0 in New Jersey.<sup>25</sup>

#### **Childhood Cancer**

• Cancer is the leading cause of death in children younger than 15 years old, second only to accidents. Seventy-eight percent of those diagnosed with childhood cancer will survive

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k Invasive and *in situ* bladder cancers are both included in standard statistical tables. See "<u>United States Cancer Statistics: 2001 Incidence and Mortality Web-based Report</u>" footnotes at http://apps.nccd.cdc.gov/uscs/TableV.asp?group=1a&Year=2001&Gender=FEM&RateType=AgeadjType&TableType=INCI#Footnotes

- five or more years. Impressive treatment and supportive care has helped to bring the childhood cancer death rate down approximately 49% since 1975.
- According to the NJ-CCCP Task Force, when a diagnosis of cancer is made in an
  individual from birth to 21 years of age, that person is best served by being treated at a
  pediatric cancer center. That center should be identified as being a member or affiliate of
  the Children's Oncology Group with the ability to enroll eligible patients in national
  protocols.
- In 1979 the Sussex County childhood cancer incidence rate was higher than the state rate (16.3 versus 14.3 per 100,000 children for county and state, respectively). The Sussex County incidence rate for childhood cancer has dropped in more recent years so that by 1995 it was somewhat lower than the New Jersey average (11.3 versus 15.0 per 100,000 children).<sup>29</sup>

# Section 4 – Discussion, Analysis and Recommendations

Cancer services delivered in the context of a statewide plan, and the activities that may be expected to be guided and flow from such a plan, imply the necessity of creating a statewide cancer healthcare system. Doing so would be a unique undertaking and may be unprecedented in New Jersey's history. A successful system of cancer services would need to evolve over time. To date, Sussex County has not had the benefit of specific planning to organize existing cancer resources into a countywide system for the optimum benefit of its residents. The recommendations below are the first that are made for the purpose of using the NJ-CCCP to initiate such planning in Sussex County and assist the creation of a statewide cancer healthcare system. In these recommendations, references in parentheses are to relevant goals (e.g., BR-1), objectives (e.g., BR-1.1), or strategies (e.g., BR-1.1.1) outlined the NJ-CCCP.

#### **Recommendations for County and Local Priorities**

For the five-year period ending in 2000, Sussex County had an incidence rate for all cancer sites combined that was notably higher than the rate for New Jersey. It is clear that Sussex County has a cancer problem that must be addressed. With two hospitals located in Sussex County (Saint Clare's and Newton Memorial), there are significant resources available to provide screening, detection, treatment, and education services.

The state's new regulation established in February 2003, N.J.A.C. 8:52 Public Health Practice Standards of Performance for Local Boards of Health in New Jersey, calls for the creation by all boards of health of a Countywide Health Improvement Plan (CHIP). The plan is required to include the participation of non-governmental organizations that affect or are affected by public health services. Cancer services are identified in an appendix to the regulation as a candidate subject for local public health planning and action.

As discussed in Section 2, additional coordinated cancer services are needed throughout the county. There are no coordinated planning or communication efforts linking the public and private organizations in Sussex County that provide cancer services. The only cooperative relationships among cancer service providers countywide are those that exist for ancillary and tertiary care services. There is no plan for provision of cancer services in Sussex County.

The formation of the Sussex County Cancer Coalition (SCCC) makes it possible to develop countywide plans for cancer services with the participation of all of the governmental and non-governmental organizations that serve Sussex County residents with cancer-related services.

# Goal 1 – Create an organizational infrastructure [INF] to develop a Sussex County Cancer Control Plan.

SUS INF Objective #3. The SCCC has been established and is urged to adopt a mission that will contribute to the development of the NJ-CCCP; to create a countywide cancer plan that will be included in the CHIP; and to seek to implement its goals in Sussex County. The Coalition's agenda should include a review of the NJ-CCCP and formulation of a county plan that considers the needs created by the cancer burden in Sussex County. (NJ-CCCP IM-1.1.3)

# Goal 2 – Coordinate [COORD] the activities of the Sussex County Cancer Coalition with those of the Governor's Task Force on Prevention, Early Detection and Treatment.

This recommendation is the second most important priority since it is essential to the construction of a cancer system that links county activities with those of the state.

SUS COORD Objective #1. It is recommended that the SCCC coordinate its activities with those of the Governor's Task Force on Prevention, Early Detection and Treatment in New Jersey to obtain and provide information regarding the improvement of access to services. Such activities will serve to advance implementation of NJ-CCCP strategies AC-2.1.6 and AC-2.1.7 that promote collaboration with traditional and nontraditional partners to improve communication regarding access and resources for cancer education, detection, and prevention services (including research studies) and to disseminate information about the New Jersey Cancer Education and Early Detection Program (NJCEED) services.

#### Goal 3 – Initiate a program of cancer services advocacy [AD] in Sussex County.

This activity will assist in implementation of the NJ-CCCP strategies for advocacy (AD-1.1.1 and AD-1.2.2), which support advocacy for funding and support for the NJ-CCCP, including cancer awareness, education, early detection programs, access to care, and for the promotion of collaboration with relevant organizations.

<u>SUS AD Objective #1</u>. It is recommended that the goals and objectives of the NJ-CCCP, in conjunction with information provided in this report, be incorporated into the Sussex County CHIP. Further, this information should become the subject of public policy advocacy for funding – influencing Sussex County services origination, expansion, and education to municipal government, the Sussex County Freeholders, and Sussex County representatives to the State Assembly and Senate.

## Goal 4 - Create a Sussex County Cancer Control Plan [PLAN].

A Sussex County Cancer Control Plan should be the product of numerous individuals and organizations that work in a common effort to plan and strengthen the cancer services system in the county. The foregoing efforts described as part of Goals 1-4 are regarded as necessary predecessors to recruiting and training many of the planner participants. For that reason, the creation of the county's cancer plan is listed here as the fifth priority. It is anticipated that planning activities will begin immediately through the Sussex County Cancer Coalition.

Goal 5 – Use the new Sussex County Cancer Coalition to enlist healthcare providers in: (a) tobacco-related treatment, and (b) changing patients' unhealthy behaviors. [NJ-CCCP: LU-1.1.1; NP-1.3.1]

Goal 6 – Increase the use of computer-based resources, including online support groups, by County residents with cancer. [NJ-CCCP: AC-1.2.3]

- (a) Publicize online support groups and eliminate obstacles to their use.
- **(b)** Make use of the resources of the New Jersey Self-Help Clearinghouse. This non-profit service of Saint Clare's Health System, funded by the New Jersey Division of Mental Health Services, provides information by telephone on over 4,500 local self-help groups in New Jersey as well as assistance in starting new local self-help groups.

Goal 7 – Target outreach efforts to county physicians to change patients' unhealthy behaviors. [NJ-CCCP: NP-1.3.1]. For example, the new Sussex County Cancer Coalition could be used to enlist healthcare providers in tobacco-related treatment. Low rates of tobacco cessation counseling remain an ongoing problem; in the year 2000, only one-third of adults who talked with a physician were asked if they smoke or use tobacco.<sup>27</sup> Working through physicians could be particularly effective since it is reported that 70% of smokers visit a healthcare provider each year, thus allowing for considerable patient/provider contact.<sup>27</sup>

Goal 8 – Encourage the use of existing county programs and resources related to lung cancer [NJ-CCCP: LU-2.2.2]. Promote programs such as the Quitcenter (for current smokers) as well as Sussex County Communities Against Tobacco (C.A.T.) and REBEL to decrease the initiation of tobacco use by both youth under 18 years of age and youth 18 to 24 years of age. Such programs should focus particularly on Sussex County females, who have been designated as the highest priority by the National Cancer Institute.

# Goal 9 – Initiate breast cancer outreach efforts, especially to senior women, based upon approaches with demonstrated effectiveness.

- A. Outreach Opportunities [NJ-CCCP: BR-1.3.4].
  - Work with local businesses and organizations.
  - Partner with radio and television stations.
- B. Cancer Education Messages [NJ-CCCP: BR-1.3.2, BR-1.1.3]
  - Education messages should strongly point out the benefits of mammograms and the dangers of avoiding them. Use specific campaigns, recommended by the National Cancer Institute.
  - Use targeted mailings to female seniors, the population of focus in Sussex County.

# Goal 10 – Implement at least one evidence-related recommendation for each of the additional priority cancers.

- A. Cervical [NJ-CCCP: CE-2.1; CE-1.2]
  - 1. The SCCC should implement education efforts about risk factors and available resources for screening on behalf of women over age 50 since they have a higher percentage of late-stage diagnoses than their statewide age cohort.
  - 2. Identify at-risk individuals that are program-eligible in their municipalities and facilitate their access to NJCEED services.
- B. Colorectal [NJ-CCCP: CO-1.1; CO-1.2]
  - 1. Direct SCCC screening efforts to all men and women over 45 years of age with an emphasis on male seniors. Encourage performance of the FOBT and colonoscopies.
  - 2. Although screening and early detection are important in the successful prevention and treatment of colorectal cancer, colorectal cancer screening is less widely used than screening for other cancers. Healthcare providers need to recommend at least one of the appropriate screening options for all eligible patients. Evidence suggests that when a screening recommendation comes directly from the clinician, compliance with colorectal cancer screening can be quite high.
  - 3. Make risk factor education and information about screening resources available to people of all ages.
  - 4. Identify health attitudes and priorities of populations of focus. The high percentage of late-stage detections for colorectal cancer among males and females suggests that many persons with cancer defer their requirements for healthcare services until their situation is urgent.

#### C. Melanoma [NJ-CCCP: ME-1.1; ME-2.1; ME-6.1]

- 1. The SCCC should initiate a broad melanoma awareness campaign that includes the subject matter suggested by the New Jersey Melanoma Workgroup. All residents of the county should receive this information. Special emphasis should be given to providing information to Sussex County healthcare professionals regarding state-of-the-art treatment for melanoma and to schools to achieve prevention of its occurrence.
- 2. The SCCC should evaluate the several Centers for Disease Control (CDC) population-based interventions to prevent skin cancer such as the national campaign *Choose Your Cover*. Such programs might be adapted for outreach to persons engaged in outdoor employment and recreational activities. These programs should also be incorporated into the school health curriculum for the purpose of influencing social norms regarding sun protection and tanned skin.
- D. Oral and Oropharyngeal [NJ-CCCP: ME-1.1; ME-2.1; ME-6.1]
  - 1. Direct screening efforts to all men and women because, as the NJ-CCCP reports, "too few people have regular oral and oropharyngeal cancer exams and too few dentists and physicians are routinely screening for it." Special outreach efforts to increase awareness of the need for screening and defined access to it should be directed to long-term users of alcohol and tobacco.

- 2. The SCCC should consider guidance from the Oral Cancer Consortium (www.oral-cancer.org) as it attempts to increase professional knowledge about oral and oropharyngeal cancer.
- 3. SCCC should support the NJ-CCCP suggestion concerning advanced training programs in oral medicine in medical and dental schools throughout New Jersey. NJCEED programs' use of bachelor's-prepared RNs who are specially trained in such techniques may be one way to increase access to screening, especially in medically underserved areas of the state.

# E. Prostate [NJ-CCCP: PR-1.1; PR-4.1; PR-4.2]

- 1. The SCCC should: (a) assist physicians and residents to maintain state-of-the-art awareness about prostate cancer screening and treatment recommendations because of the controversies that exist regarding these topics, and (b) support the development and implementation of an up-to-date database of prostate educational opportunities for practitioners as suggested in the NJ-CCCP. (It is recommended that the database contain information about opportunities such as that provided by the National Comprehensive Cancer Network.)
- 2. The SCCC should initiate an expanded outreach effort to both older men and black men to increase awareness of their increased risk for prostate cancer and the resources available to them. Such education is available through NJCEED's use of the national *Going to the Barbershop to Fight Cancer* Program.
- 3. Since prostate cancer screening and follow-up treatment are available to eligible individuals through NJCEED, a concerted effort by members of the SCCC should identify individuals at risk for this cancer that are programeligible in their municipalities and facilitate their access to NJCEED services.

#### **Recommendations for Statewide Priorities**

The NJ-CCCP envisions the creation of an organized cancer service system. The system that is developed should consist of expanded cancer services that are available to all who require them. The building of such a system will require additional resources. These resources must be organized in a manner that involves and supports the additional people who will be required to initiate and manage the system in a manner that maintains and enhances existing services while adding to them. Such an effort presupposes that the New Jersey Department of Health and Senior Services and others from throughout New Jersey become organized for communication and action and are provided with the information and financial resources required to initiate a system of this kind. The system-building effort will require the formation of additional organizations such as the Sussex County Cancer Coalition, as well as the recruitment of new individuals who will carry out activities essential to the development of the system. At this time, the New Jersey Department of Health and Senior Services is charged with the planning and implementation of this system.

# Goal 1 – Strengthen and support the Sussex County Cancer Coalition and others throughout the state [ORG].

SUS ORG Objective #1. Create coordinated DHSS state and Sussex County Cancer Coalition agendas.

SUS ORG Objective #2. Fund the Sussex County Cancer Coalition and hold it accountable for agenda operations.

SUS ORG Objective #3. Adopt the New Jersey Comprehensive Cancer Control Plan as state policy.

SUS ORG Objective #4. Publicize the New Jersey Comprehensive Cancer Control Plan.

#### Goal 2 – Strengthen and support local cancer service delivery programs [SVCS].

*SUS SVCS Objective* # 1. Strengthen the Sussex County NJCEED Program, enabling it to provide additional services.

SUS SVCS Objective # 2. Increase the participation of all New Jersey hospitals with the provision of low-cost and free cancer care.

SUS SVCS Objective # 3. Utilize county cancer coalitions for education.

It is recommended that the NJDHSS support the county cancer coalitions to educate healthcare providers about the services available in Sussex County and elsewhere in New Jersey.

# **Closing Remarks**

The Cancer Capacity and Needs Assessment provides a detailed baseline assessment for Sussex County. The data, interpretations, and recommendations in this report were developed to provide a wide array of public health and medical personnel with standardized information and detailed analyses that can help guide and focus their efforts at the county level, including such local health initiatives as the forthcoming Community Health Improvement Plans. The reports from all of the counties will collectively inform the continuing comprehensive cancer control efforts of the Office of Cancer Control and Prevention of the New Jersey Department of Health and Senior Services; the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey; and the University of Medicine and Dentistry of New Jersey.

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